



KENTUCKY CANCER REGISTRY

Year Funded	Type of Program	Affiliation	Compliance with Public Law 102-515: Legislation and Regulations*	
1994	Enhancement	Univ. of Kentucky Research Foundation	Authorizing legislation for a statewide registry: Yes	Regulations in place for data reporting, confidentiality, and use: All

*Source: NPCR Legislative Database, January 2001.

Cancer Burden

Cancer is a devastating disease. According to the American Cancer Society, in 2001 an estimated 553,400 Americans will die of cancer, and approximately 1.3 million new cancer cases will be diagnosed. These estimates do not include in situ (preinvasive) cancer of any site except urinary bladder or approximately 1 million cases of nonmelanoma skin cancer to be diagnosed this year. In Kentucky, an estimated 21,100 new cancer cases will be diagnosed, and approximately 9,200 will die of this disease in 2001. Kentucky ranks 4th highest overall in cancer mortality rates among the 50 states and Washington, D.C.*

The NPCR

Cancer surveillance involves the systematic collection, analysis, and use of cancer data. Information derived through surveillance is critical for directing effective cancer prevention and control programs. The Centers for Disease Control and Prevention's **National Program of Cancer Registries (NPCR)**, authorized by Congress in 1992 through the Cancer Registries Amendment Act (Public Law 102-515), serves as the foundation of a national, comprehensive cancer control strategy. Statewide cancer registries provide critical data to help identify and monitor trends in cancer incidence and mortality over time; guide cancer control planning and evaluation; help

allocate health resources; and advance clinical, epidemiologic, and health services research.

Through the NPCR, CDC supports registries in 45 states, the District of Columbia, and three territories, representing 96% of the U.S. population.[†] Forty-five programs receive support to enhance existing registries; these have on-going cancer data-collection activities, policies and procedures for central registry operations in place, and core staff employed. Four programs receive support to plan and develop new registries; they are typically involved in laying the necessary groundwork for establishing a central, population-based registry.

With fiscal year 2001 appropriations of approximately \$36 million, CDC continues to support and enhance state cancer registries, and promotes appropriate uses of data. The CDC will also develop special research projects, such as studies of patterns of cancer care in specific populations and assessments of data for integration with geographic information systems.

State Highlights

- The Kentucky registry was certified by the North American Association of Central Cancer Registries for completeness, timeliness, and quality of its 1997 data.
- The Kentucky registry is one of 11 registries participating in a special

NPCR-supported childhood cancer project to design, implement, and evaluate a method to use data from a state population-based central registry to compute expected numbers of incident cancer cases in children. The registry will evaluate completeness of its data and of other existing pediatric cancer databases, such as the Children's Oncology Group, by performing data linkage.

- Kentucky was able to save thousands of lives and millions of dollars with its cancer registry. In the early 1990s, 35% of Kentucky women diagnosed with breast cancer had advanced (late-stage) disease, for which the survival rate is low. Registry data were used to identify areas of the state that had high rates of late-stage and low rates of early-stage breast cancer. In 1994, Kentucky received CDC funding to enhance registry and breast and cervical cancer activities, enabling the state to expand mammography outreach activities in these communities. In 1996, the percentage of Kentucky women diagnosed with late-stage breast cancer had declined to 30%. In addition to the potential lives saved by detecting these cancers earlier, Kentucky estimates that it has saved more than \$4.7 million in treatment expenditures.

Continued

*Source: CDC's National Center for Health Statistics, vital statistics data, underlying cause of death, 1993-1997.

[†]A map of the participating NPCR programs can be found at <http://www.cdc.gov/cancer/npcr/statecon.htm>.

KENTUCKY, CONTINUED

- A current pilot study on ovarian cancer will use data collected by the Kentucky Cancer Registry to obtain information on risk factors associated with ovarian cancer. Researchers have identified various reproductive risk factors for ovarian cancer, but little is known about how these risk factors initiate or promote tumor development. It is possible that different types of tumors may be triggered or promoted by different risk factors. If so, a significant association may exist between specific risk factors and particular molecular alterations found in the tumor DNA.

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